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ABSTRACT

This study examined expenses associated with providing the Lovaas behavioral therapy for children with autism as well as the amount and type of stress parents perceive in raising an autistic child. Parents (12 mothers and 10 fathers) of autistic children (mean age 56 months) completed a self-report questionnaire. Expenses associated with the therapy included the initial consultation, a 3-day training workshop for parents, rearrangement of the home environment to foster therapy, hiring of therapists (mean number 5 per family for a mean number of 29.5 hours per week), and follow-up consultations. Parents estimated the average monthly cost of providing therapy for their autistic child to be $1,237. Responses concerning family adjustment and stress indicated many families have a highly structured routine for their autistic child, both mothers and fathers perceived high levels of stress, most parents reported spending 0-3 hours together per week, the autistic child frequently had additional health problems, and financial assistance defrayed only a small percentage of treatment expenses. Discussion focuses on recommendations for additional government funding and insurance coverage for families of autistic children. (DB)

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The Economic and Psychological Burdens Associated with Lovaas Treatment for Childhood Autism

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Autism is a rare and still mysterious disorder, affecting one child in every 10,000 births. The term autism was coined by Kanner in 1943. Kanner observed in a particular group of children a serious failure to develop relationships with other people before 30 months of age, problems in development of normal language, ritualistic and obsessional behaviors, and a potential for normal intelligence (Lovaas, 1987).

With the etiology of autism remaining uncertain, finding useful treatments has been difficult. Of the many therapies available, behavior modification developed by Lovaas appears to produce the best results. In a study done by Lovaas, it was shown that an experimental group of autistic preschoolers receiving intervention achieved less restrictive school placement and higher IQ's than did a control group of 19 similar children by age 7 (Lovaas, 1987). Follow-up studies have provided further support for his findings (Frith, 1993; Frith, 1989). While several treatment methods for autism exist, Lovaas therapy is one of the few treatment methods that has been studied fairly extensively. The rarity of this disorder has made it difficult to conduct well-controlled, large scale outcome studies. Although no method has been shown to "cure" autism, the Lovaas treatment method seems to be the most effective means of reducing maladaptive symptoms of autism and allowing autistic individuals the opportunity to lead fairly normal and productive lives.

The current study was conducted for two purposes. First, by providing empirical data on the expenses associated with Lovaas therapy, this research can contribute to deliberation about the

need for increased funding of Lovaas programs. Secondly, this study examined the amount and type of stress parents perceive in raising and autistic child, and whether these levels of perceived stress differ between mothers and fathers.

Method

Subjects

The participants were 12 mothers and 10 fathers of autistic children in Montgomery County, PA and the surrounding region. All families were using the Lovaas treatment approach with their autistic child at the time they completed the questionnaires. Sixty-seven percent of mothers were unemployed, 25% employed part-time, and 8% employed full-time. All of the fathers were employed full-time. The average annual family income was $67,500. None of the respondents were in the lowest income bracket (0-$20,000 annually) and only one family was in the next to the lowest income bracket ($20,000-$40,000 annually). The majority of respondents (42%) were in the highest income bracket ($80,001 and above annually).

The average age of the autistic children at diagnosis was 34 months; average current age of children was 56 months. Thirty-four percent of the autistic children had one sibling, while 67% had two or more siblings.

Procedure

A 30-item self-report questionnaire used in a previous study (Chambliss and Doughty, 1994) of parental effects of autism was revised to focus on questions about difficulties in raising an autistic child, time constraints placed on marital and "normal"-

child/parent relationships, parental perception of levels of stress, and the financial aspects of treatment. The questionnaire was kept brief to improve return rates. The edited questionnaire was comprised of 15 structured items. Thirty sets of surveys were mailed and 40% of those contacted responded.

Results

When a family decides to employ the Lovaas method of behavioral therapy, they begin with an initial consultation with professionals to determine whether the child will benefit from this particular therapy. In the survey sample, the price of the initial consultation ranged from no cost to $1500 (avg. cost=$300). Along with the initial consult, families must attend a Lovaas workshop. In a brochure from Dr. Lovaas and the UCLA clinic for the Behavioral Treatment of Children, it is recommended that families attend (at least) a three-day workshop. The fee for a three-day, non-local workshop (at the UCLA clinic) is $2000 plus airfare, hotel and expenses (UCLA Dept. of Psychology, Workshop Information Packet). The survey respondents' workshop expenses ranged from a flat fee of $200 per day to $100 per hour for each of three days.

After the workshop is completed, families must create a work schedule for their child. Since the Lovaas method requires that the initial therapy take place in the child's home, families must create an atmosphere that will be beneficial to their autistic child's learning process. This requires that families fit their schedule to that of the child's therapy sessions. It is also necessary to hire therapists. This can be time-consuming, because therapists must be screened and trained. In the current study, the

average number of therapists was 5, with a mean salary of $7.60 per hour for 29.5 hours per week (mean hours).

As part of the treatment, it is necessary for the progress of each child to be monitored. This is done by scheduling periodic follow-up consultations. In the Workshop Information Packet, it is suggested that consultations be scheduled every 12 to 16 weeks for 2-3 hours, at the same cost as the initial workshop ($2000). Data from the survey respondents show that consultations are scheduled, on average, every 3.8 weeks, at an expense ranging from $60 per hour to $260 per hour. Consults are typically one and a half hours long. Parents estimated the average monthly cost of providing therapy for their autistic child to be $1237.

The second part of the survey focuses on the constraints an autistic child may place on their family. Having an autistic child in a family can be very difficult. The amount of time and resources required for treatment often create high levels of stress and adjustment complications. In the current study, adjustment was explored by examining the family structure. Autistic children have very inflexible lifestyles. It was found that the majority of the families (58%), reported that they often have a structured routine for their autistic child, while 25% said they always followed a structured routine. The majority of these families also reported a need to regularly discipline their autistic child.

In the current study, questions were asked of mothers and fathers separately, to assess the amount of support they received and to determine if the levels of stress perceived decreased with an increase in social support systems. It was found that although

mothers indicated that they utilized more support systems than fathers (such as parents, friends and co-workers), this made no difference in their perception of their high levels of stress. Fathers utilized mainly a spousal support system, and also reported high levels of stress. It was interesting to note that although 100% of the male respondents reported discussing their child's condition with their wife, only 75% of the female respondents reported discussing the child's condition with the husband.

In questions that addressed the amount of time that spouses spend together per week, 60% of fathers and 67% of mothers reported spending 0-3 hours together per week. The average amount of time spent with non-autistic children per week for women was 6.3 hours, and for men 6.6 hours. Even though responses indicated that mothers have more responsibility for their autistic child than fathers, the amount of time spent with their other children was fairly equal between mothers and fathers.

It is difficult enough to raise a child with autism, but several of the families in this survey listed additional health problems that affected their autistic child. Problems included feeding (difficulty swallowing and chewing, refusal to eat); sensory (child does not know what is hot, will not cry even if bones are broken, extremely high tolerance for pain); behavioral; hearing impairment, blindness, epilepsy and severe mental retardation.

Sources of funding for participating families in the current study included Medicaid, the County Intermediate Unit, the County, MHR-Settlement, Montgomery County Driven Program (receive $200.00

once a year), Help Counseling, and Montco IU Funds. Although 67% of the families received some type of government funding, the funding that is provided defrays only a small percentage of treatment expenses. There are a number of items that must be taken into consideration in estimating the cost of autistic child care, such as diapers expense, babysitting fees, treatment expenses, and traveling fees. The average salary per hour for babysitter was $6.00 in this study. This may be one factor contributing to the small amount of time parents spend alone with each other, thus increasing the marital stress of having an autistic child.

Discussion

Additional government funding should be made accessible to all families of autistic children. It is important that the government adopt federal standards for the treatment of autistic children. Having this standard, and specific organizations trained to regulate treatment programs, would help reduce the variability in treatment cost. It would also help make treatment more affordable for all autistic families. Further, the amount of research time families need to invest would decrease, thus allowing for more time for the family to be together. In this study, the mean amount of time spent researching autism was 555 hours.

Also, insurance companies need to be encouraged to help cover some of the expenses of different treatment components. In the current study, only 25% of the families' insurance policies helped defray treatment cost. Allergy treatment and swallowing/feeding therapy were among the costs covered. However, for the majority of the families (75%), insurance companies did not cover treatment

costs.

Besides the Lovaas treatment therapy, there are a number of additional therapeutic strategies that may assist autistic children. In the current study, 58% of the subjects were involved with occupational therapy, 50% speech, 25% sensory integration, 25% classroom, 17% physical, and 8% participated in the following: behavioral, autistic support pre-school, school placement, swallowing, play, and music classes. In the current study, 83% of the children were involved in an extended school year program, while 17% did not attend an extended school year program. These treatment costs impose additional financial burdens on autistic families.

In general, both mothers and fathers believe that their child places a great deal of stress on the family. For women, 92% reported the child was (always to frequently) stressful, and for men, 90% reported the child was (always to frequently) stressful. Men and women may experience different types of stress in parenting the autistic child. Here, women reported they were "always" involved in the treatment of their autistic child 83% of the time, compared to fathers who answered this way only 20% of the time. Responses suggested that fathers may be most stressed because thy may not see the progress the child is making. On the other hand, mothers seemed most stressed because they feel more responsible for overseeing the care of their children.

Also, the non-autistic sibling, competing for attention, may be another source of family stress. In the current study, both fathers an mothers believed that their non-autistic child competed

for attention (78% of the time according to fathers, and 83% of the time, according to mothers).

Providing additional funding for autism treatment might facilitate care of non-autistic siblings, by reducing the number of hours parents must spend in employment. This could liberate additional time for parents to share with their non-autistic child, possibly reducing destructive competition for attention. With additional resources, these highly challenged families would have an easier time balancing the urgent competing needs of their members.

References

Frith, U. (1989). Autism: Explaining the Enigma. Blackwell Publishers.

Frith, U. (1993). Autism. Scientific American, p. 108-114.

Lovaas, O. (1987). Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children, Journal of Consulting and Clinical Psychology, 55,(1), 3-9.